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Narrative literature and cancer: improving the doctor-patient relationship

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ABSTRACT

The role of classical literature on the subject of pain and suffering in cancer and other serious illnesses, not only from the point of view of patients but also hospital personnel, family, friends and family doctors, has not been deeply exploited to favor the human and professional experience of young and not so young oncologists. This manuscript is the result of an effort made by postgraduate students and faculty members at the School of Oncology at Parma University to review the literature on this subject. The aim of our work is to convey the message that before teaching relationship techniques it is important to instill a culture focused on the doctor-patient relationship. Classical literature can make an important contribution to awareness in this area.

The desperate experience of cancer causes each of us, whether young or no longer so, to see the world from a new perspective. In some cases cancer patients live every day knowing that the outcome may not be positive; this eventuality becomes their constant companion and interlocutor. Often this is also true for family, friends and those assisting the patient. Patients and individuals close to them become part of a community which has no connection to everyday life because challenges, pain and fear dominate. As in war, with cancer we do not know who the final victor will be. It is essential that doctors acquire the ability to get to know and interpret the patient's world in order to establish a good doctor-patient relationship, and although this world may vary from patient to patient, there are several common characteristics[1-7].

One of the goals of a lecturer in clinical oncology at the university is to understand how much importance our young colleagues attribute to the doctor-patient relationship and one is never totally sure which approach to take nor which instruments should be used to hit the mark. For many years no attention was given to developing specific training programs in this field for oncologists. The question is how to train young and sometimes experienced oncologists in doctor-patient relationships. To begin with, residents in oncology should be asked whether they have read some of the texts which are considered essential to understanding the feelings and emotions of cancer patients and their families.

Recently a program was introduced at the University of Parma School of Oncology to integrate classical narrative literature into a training program to be used as a basis for role-playing situations where doctors and nurses are directly involved in the performance. Where possible, participants are divided into medical oncology and palliative care groups. A team consisting of doctors, nurses and psychologists are asked to perform, for example, *The Death of Ivan Ilyich*, and participants of both groups are invited to select the role to be played in the scene. After reflection the participants give feedback while the team only intervenes to facilitate the process. The results of this training program are not currently available. However, so far they have been encouraging since many participants have reported feeling more confident when confronting the difficult task of communicating bad news or accompanying a patient in the final stages of life. Given the initial encouraging enthusiasm of the participants in this program, our intention is to make it an integral part of the course.

Key words: narrative literature, cancer, doctor-patient relationship.

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Francesca Fornario, a young Italian author, in 2001 wrote with derisory and irreverent tones a scenario by the provocative title *The Time to Die*. Zitto, the main character, doesn't believe in anything. He is convinced to have neither a conscience nor cancer, only to find out, at one and the same time, he has both, the cancer being stronger than his conscience. He says, "Cancer is that type of illness which leaves you time to contemplate your life."

Time is everything for the cancer patient; therefore one of the doctor's most important tasks is to understand the dimensions of the patient's time and its relativity, and to empathize with him or her.

Tolstoy's short story *The Death of Ivan Ilyich* (1886) includes a detailed description of the phenomenon and subjectivity of cancer as well as the disappointing reactions of doctors and those close to the patient. "Those lies, lies told to him and about him as he was dying, destined to diminish that terrible, solemn act during their visits to him… were a terrible agony for Ivan Ilyich."

The cancer patient is vulnerable, fragile and only too aware of the gravity of his or her condition and needs to be comforted not with false hope or lies but with empathy, understanding and as much honesty as possible from the doctor who will accompany them to the end of life[8-13].

Luigi Pirandello, in his work *The Man with the Flower in his Mouth* (1923), depicts a man looking at himself in the mirror one morning when he realizes that he doesn't recognize himself because the day before he had been told by his doctor to have only a few months left to live owing to a ravaging disease. From that moment everything changed for him: the way he looked at the world, the way he looked at his life and the lives of others. All of a sudden, the infinitesimal details of everyday life assume an incredible importance for the simple reason that he knows he is going to lose them forever. The scene is well known. The protagonist and a peaceful businessman who has missed his train and has all the time in the world are sitting at a little table in a modest all-night café.

> "My dear sir, come here under this street light, come, I'll show you something. Look here, under this moustache, here, do you see this purple flower? Do you know what this is called?
> Ah! It's a very sweet name, sweeter than a sweetie: Epithelioma it's called. Say it, you'll hear how sweet it is; e-pi-the-li-oma. Death, you understand. It came to see me and it shoved this flower in my mouth and said, hold on to this my dear, I'll be back in about eight to ten months."

The man with the flower in his mouth takes his cue to begin a series of reflections on existence. Knowing when and how we will die is one of the most despairing experiences a person can go through.

In *Cancer Ward*, a story by Alexandr Solzhenitsyn published in 1967, set in the post-Stalin Soviet Union, the protagonist Oleg Kostoglotov spends time in the oncology department of a hospital in central Asia. Kostoglotov is the alter ego of the author, who underwent surgery several times for gastric cancer. In the cancer ward the protagonist meets a series of characters including other patients, nurses and doctors. Human stories, totally and profoundly different, but with one thing in common: the disease and a destiny they did not expect. *Cancer Ward* talks about life, death, love and existence, ethics and politics. It is one of those books which poses the fundamental question we sometimes forget to answer: What do men live for? This story represents man's solitude, highlighting how difficult it is to communicate even when individuals are together in the same room, in the same situation.

Physical suffering leads to crucial questions and doubts about existence, fear and the meaning of death, whether there is life after death, the sense of suffering and pain, the meaning of disease and recovery.

The novel by Philip Roth *The Dying Animal* (2001) is very interesting from this point of view. David Kepesh, the main character in the novel, is a famous university professor, but disillusioned, a pleasure-seeker leading a libertine life. His inflexible rule is not to bind himself to one woman. However, at 60, he meets Consuela Castello, a brilliant young student with a perfect body, who becomes involved in the erotic raptures of the old professor. The girl's body becomes his sexual and mental obsession and, for the first time, he feels old and defeated. Kepesh's last meditations are about the sight of death in the evidence of the marks left on the body, marks such as those left on Consuela's body destroyed by breast cancer. Death is measured by the physical appearance of the body and has the visual power of the present, signifying the loss of that virgin beauty represented by Consuela's body. The evidence of death breaks the physical balance between body and mind. Kepesh recognizes this in Consuela when he feels the girl's mind has detached from a body consumed by the signs of cancer. He realizes, through the young woman's words, the deep anguish of this separation.

Coming face to face with death provokes in us questions which are difficult if not impossible to answer, as we can see from the final line from the movie *Shadowlands* (1993, inspired by CS Lewis's published diaries *A Grief Observed*, 1960), which illustrates perfectly the enigma which is life.

> "Why love if losing hurts so much? I have no answers any more. Only the life I have lived. Twice in that life I've been given the choice: as a boy and as a man. The boy chose safety, the man chooses suffering. The pain now is part of the happiness then. That's the deal."

From the works cited here, which represent some – but by no means all – of the narrative literature dealing with

cancer, it becomes obvious how knowing, understanding and attempting to interpret this literature can enrich the doctor in the development of his or her relationship with patients[14,15]. Can we begin to imagine the positive effect good communication skills would have had in terms of the doctor-patient relationship in professional situations such as those represented in the cited classical literature? Certainly, most oncologists will have experienced such situations and, as described by Back *et al.*[16], "the patient from hell" has left them feeling totally inadequate in their relationships with patients. This is why training programs where *i)* attention is given to the setting of the meeting, *ii)* a doctor has to deliver "bad news" with no distractions or interruptions, *iii)* contemplation and silence are given their proper place, *iv)* the body language of the patient and the doctor can be observed, understood and interpreted correctly, and *v)* empathy is the doctor's main focus, are essential in order to acquire good communication skills. To quote Kafka, "It's easy to write a prescription for medicine but talking to people who are suffering is more, much more difficult."

In conclusion, we believe that a training course centered on the types of situations found in the narrative literature mentioned should be part of specialization courses in oncology.

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